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ABSTRACT

Federal legislation and programs affecting personal assistance services for persons with disabilities are examined. Personal assistance services may be provided for activities of daily living, communication, cognitive tasks, or mobility, depending on the needs of the individual. The population in need of attendant services has increased with advances in medical treatment and emergency services, but precise data on the number of persons are not currently available. Available funding sources include Medicaid, Medicare, Rehabilitation Act of 1973, Veterans Administration programs, Education for All Handicapped Children Act, and others. Issues in the provision of personal assistance services include: definition of certain tasks as medical or nonmedical, eligibility requirements, systems for delivery of services, funding, and the cost of meeting the demand for attendant services. Recommendations call for implementation of a cost-effective process for supporting community-based personal assistant services for persons with severe disabilities, and establishment of a national policy that makes personal services accessible for people with all types of disabilities on the basis of functional need. (JDD)

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TOPIC PAPER 1:

PERSONAL ASSISTANCE: ATTENDANT SERVICES, READERS, AND INTERPRETERS

National Council on the Handicapped

February, 1986

EC 211166

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This is one of a series of ten topic papers developed by the National Council on the Handicapped as part of its Special Report to the President and Congress: TOWARD INDEPENDENCE: An Assessment of Federal Laws and Programs Affecting Persons with Disabilities--With Legislative Recommendations. The members of the National Council on the Handicapped wish to expressly acknowledge with appreciation the special contribution made to this paper by Margaret A. Nosek.

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I. INTRODUCTION

Personal assistance is the key to independence for hundreds of thousands of Americans with disabilities. Assistance provided by other persons on a one-to-one basis can enable those with even the most severe disabilities to have opportunities for self-direction and productivity in a setting of their own choice. Many people who need these services, however, are unable to receive them because of a lack of awareness of what personal assistance is, the unavailability of appropriate services in their area, and, most often, a lack of funds to purchase needed services. Often the personal services that prevent placement in institutions are vital to the very maintenance of life for severely disabled people. Because so many environmental factors prevent persons in need from receiving this service, the situation warrants a substantial, coordinated, and effective Federal presence.

Personal assistance services include assistance in carrying out those activities of daily living which, because of functional limitations, individuals are unable to adequately perform for themselves. These limitations may be caused by physical, sensory, mental, or developmental impairment and are usually of long-term duration. Personal assistance can be given in three primary areas: attendants provide assistance for activities of daily living, including basic personal self care tasks such as personal hygiene, dressing, grooming, eating, drinking, using and caring for assistive devices, and mobility; and home care tasks, such as cleaning, laundry, shopping, and meal preparation. Communication assistance, provided person to person and via

print, requires the assistance of interpreters and readers. Assistance for cognitive tasks, such as managing finances, planning, and making decisions, requires the assistance of personal advocates. Persons who are blind or have visual impairments require the assistance of technological aids or another person for mobility and for access to printed communication.

This assistance can be acquired in various degrees of formality. On the most informal level, relatives, friends, or other volunteers can be recruited to read aloud personal correspondence, newspapers, magazines, or to assist the individual in getting around the community. Some organizations, such as churches, independent living centers, or civic groups may have organized programs to recruit and refer volunteers to do this type of service. On a more formal level, organizations specifically serving blind persons may refer readers and other types of assistants on a fee-per-hour basis. Requests can also be made of volunteer and fee-for-service organizations to have lengthy documents read on to tape or brailled.

Persons who are deaf or have a hearing impairment require the services of interpreters who are skilled in various forms of sign language. Manual communication may take the form of finger spelling (this is sometimes used exclusively with persons who are both deaf and blind), signed English, American Sign Language (which has a different grammatical structure from English), or a combination of these. Interpreters may also be used to reproduce the spoken word orally for the benefit of deaf persons who are

skilled at lip reading. Each of these types of communication requires considerable training and testing for various levels of certification before interpreters can serve deaf persons. Interpreting is a bona fide profession with formal training programs, a code of ethics, professional organizations, and boards to regulate the certification process. Fees for interpreter services vary according to the level of certification. Methods for acquiring the services of an interpreter vary according to local service systems. Some cities have a deaf services agency or independent living center which can refer interpreters and often offer education and counseling services. Deaf people in cities which have no such agencies or centers can sometimes go through the State vocational rehabilitation agency to obtain interpreter services. If even this is not available or if funding for the service is not available, persons with hearing impairments must rely on less formal means to meet their communication needs, such as requesting assistance from relatives, friends, or neighbors.

Persons with mental retardation can often live on their own or in small groups if some degree of periodic supervision is available to help them with the cognitive tasks necessary for independence. Because certain of these tasks involve handling money and making decisions in critical personal areas, persons who provide this type of assistance must meet strict standards of integrity and responsibility. Some local Associations for Retarded Citizens offer programs which link "proteges" (mentally retarded persons) with advocates (responsible adult volunteers).

More formal arrangements are sometimes made through residential institutions and community group homes.

Across these four areas, persons who need personal assistance share many of the same problems, such as inadequate funding and the unavailability in many parts of the country of persons to provide this assistance. For the purpose of brevity and clarity, the detailed discussion below is limited to the topic of attendant services. The recommendations presented in this report, however, refer to all types of personal assistance, including communication and cognitive assistance.

II. THE POPULATION IN NEED OF ATTENDANT SERVICES

With advances in medical treatment and emergency services, an ever greater number of persons are surviving catastrophic illnesses and injuries, often with physical impairments that limit their abilities to perform many of the functions necessary in everyday living. In addition to this post-trauma/post-illness group, a significant number of children are born each year with impairing conditions, including genetically-related neuromuscular disease, mental retardation, and congenital conditions resulting from insult to the unborn child in utero or during birth that limit function and ability to perform activities of daily living. When the number of persons in these groups are added to the number of elderly persons who experience increasing disability resulting from the functional losses associated with various diseases, a substantial number of people with functional impairment require some assistance in performing activities of daily living.

Although data on the actual number of persons requiring attendant assistance on a national basis are not available, it can be safely assumed to be in the millions. Bowe (1984) states that there are 13,102,000 persons between the ages of 16 and 64 with a "work disability." While not all of these persons have disabilities requiring the services of an attendant, it is not unrealistic to assume that a significant percentage does require such services. Existing information from the Health Interview Survey (1979) identifies persons who need "some assistance in four or more activities" as 1% - 1.2% of the population.

However, there is no indication of the extent of these activities; for example, persons who need 20 minutes of assistance per day in minor activities and who probably would not use attendant services are not distinguished from those who need several hours of assistance per day with basic daily living activities and who use attendant services.

In California alone, 100,000 people receive funding for in-home support services, a large part of which are attendant services (Zukas, Cone and Leon, 1984). Sager and DeJong (1977) estimated that for Massachusetts, 34,600 working age adults need help on a regular basis in one or more activities of self care. DeJong (1985) states that the demand for attendant services among working age persons (18-64) can be estimated at 150 persons per one million total population. This estimate assumes that a person needs a minimum of 14 hours of attendant services a week.

The major flaw in most methods for gathering data related to attendant service needs is that they assume need is primarily based on function. Research has shown that functional capacity accounts for only about half of the reason why persons need this service. Family resources, environmental barriers, and availability of technological aids account for the rest.

Quantifying demand is quite different from quantifying need. Demand is a function of availability of funds, attitude toward using the service, availability of persons to provide the service, and awareness of the availability of the service. Utilization data for attendant service programs in various States suggests much lower demand during the first several years of

program operation (DeJong, 1985).

Although precise data on the number of persons requiring some form of attendant assistance in order to carry on day-to-day living activities are not currently available, it is obvious from the previous citations and available data that the number is substantial and this represents a significant need in our society. In years past, the only options available to severely disabled persons requiring self-care services were services delivered by family members or services provided in institutional settings such as nursing homes or large State-operated residential facilities. With the changing dynamics of family life, however, and the increasing costs associated with provision of services in institutional settings, these options are becoming less attractive to disabled persons, family members, and purchasers of services.

III. AVAILABLE ATTENDANT SERVICES AND FUNDING RESOURCES

The implementation of attendant service delivery systems has been characterized by considerable variation both in the structure of the systems themselves and in the mechanisms used for funding the services (Nosek, 1985; World Institute, 1985). Since most existing systems rely, at least in part, on funds provided through State-administered agencies, the actual methods for delivery and payment of services have been subject to the mandates, constraints, and idiosyncrasies of the particular legislative and agency requirements of the States in which the systems operate. This diversity has resulted in significant variance from State to State in the scope, quality, and ease of access to services. To date, no comprehensive effort has been put forth to develop a model attendant program that serves all segments of the population in a cost-effective manner while incorporating the crucial concept of consumer control.

Available funding resources are briefly described below.

- Medicaid. This is the primary source of funding for attendant services. However, it is limited by strict maximum income and asset requirements, and services generally can only be delivered under supervision of a medical professional.

- Medicare. Funds available under Medicare are time limited following hospitalization.

- Title XX. In some States, Social Services Block Grant funded programs offer attendant services. Eligibility requirements and regulations for the delivery of services are similar to those under Medicaid.

- Rehabilitation Act of 1973. Within the vocational rehabilitation system, attendant services are authorized

under Title I for persons undergoing evaluation and/or training but may only continue until a very short time after employment is secured. Under Title VII Part A, attendant services are an optional offering; however, no funds have as yet flowed to consumers under this provision.

- o Veterans Administration. Under the Aide and Attendant program, disabled Veterans are given a generous monthly allowance to purchase the services they need.

- o Education for All Handicapped Children Act, Public Law 94-142. Attendant services are funded as a related service for disabled children receiving a public education, but only while they are at school or participating in a school activity.

- o State Programs. Several States have appropriated State funds for attendant services. In some cases, these funds are used for services to persons who work or do not otherwise qualify under Federal programs. In most States, these are only pilot or demonstration programs and service a small number of people.

- o Workers' Compensation and Private Insurance. Persons receiving injury settlements under Workers' Compensation or from private insurance carriers often receive designated amounts for attendant services. In order to receive any funds for these services, the individual must often contract for more than is needed in order to meet the requirements of the payee. For example, 24 hour nursing care sometimes must be arranged in order to receive payment when only several hours per day of personal care are needed.

Some of the mechanisms through which these funds are channeled and attendant services are delivered include:

- o Home Health Agencies. Most Medicaid and Medicare funds for attendant services are channeled through State administering agencies to Home Health Agencies. After administrative costs are covered, only approximately 50% of these funds remain for direct service to the consumer (World Institute on disability, 1985). Generally, the consumer has little or no control over the choice of persons to provide the service, the type of activities assisted, or the time the service is provided.

- o Independent Living Programs. Most centers for independent living offer attendant referral services and training

certified home health providers and channel funds directly to consumers. These services offer the consumer a high degree of control over the hiring and termination of attendants and the manner in and conditions under which services are provided.

- Shared Attendant Programs. Many independent living programs and some private nonprofit organizations operate residential or transitional programs with a pool of attendants available to serve a group of consumers. Services are generally limited to persons residing in designated facilities or apartments.

- Informal Mechanisms. Although nearly impossible to estimate, a large portion of disabled persons who have needed attendant services in the past have arranged for those services through informal mechanisms such as referral by relatives, neighbors, or friends; advertising in the newspaper; use of volunteers from churches, etc. Often, rehabilitation facilities, medical professionals, social service providers, or clergy will refer people they know who may be interested in providing attendant services to disabled persons in need. Many have paid for this assistance from their own resources or through a barter system.

IV. ISSUES

The provision of personal assistance services is a relatively new and often controversial addition to service providing systems. Following is a discussion of several current issues.

A. Definition

There is controversy over whether certain tasks required of attendants are medical or nonmedical. Assistance needed in taking medicine or completing sterile procedures is regarded by medical professionals as a medical service. However, because this type of assistance can be, and often is, rendered by non-medical persons at the direction of the disabled individual, there is a strong argument for classifying it as a nonmedical service.

The definition of attendant service given earlier implies that, to the maximum extent possible, the assistance provided is controlled by the person receiving the service, and that the service is provided in the most productive and least restrictive environment. However, persons with cognitive deficits may have only a limited ability to make decisions and direct those who assist in meeting their daily needs, and may function more productively in a more structured environment. Attendant service for this population may involve supervision as well as physical assistance, though not necessarily provided by the same person.

B. Eligibility

In establishing a system of attendant services, the most desirable eligibility requirement would be based solely on functional need. Many feel the services should be available as an

entitlement to everyone who has a functional limitation which prevents them from adequately performing their daily activities. However, social and economic reality dictates that a national attendant service program will receive very limited appropriations, and will, therefore, need to institute a clear and equitable set of eligibility requirements for receiving the services.

It is the opinion of leaders in this area that this initially strict set of requirements should have functional need as the primary eligibility criterion. The determination of functional need should be based on a combination of factors, including functional abilities, family resources, environmental barriers, and the availability of technological aids. Need is also a function of life style; thus assessment can be highly value laden. There is debate over whether publicly funded attendant services should be more or equally available to working and working age disabled persons than to elderly disabled persons.

The second criterion should be financial need. Determination of financial need should include a very liberal exemption for disability-related expenses.

Given that determination of functional and financial need is complex and value laden, eligibility will be highly influenced by the perspective of the individual who makes the determination. Social workers, occupational therapists, independent living program staff, and the agency that provides the service will all have different influences affecting their decisions. Many think

that independent living programs should not provide attendant services themselves, but should advocate for the services to be provided by other community agencies.

C. Delivery of Service

There is widespread agreement that all systems for providing attendant services must allow for maximum control of the service by the consumer. Any requirements which perpetuate the medical model of attendant care in which a third party controls the provision and supervision of the service should be minimized or avoided. This raises the question of whether Medicaid funds should be used for attendant services since they are generally accompanied by requirements based primarily on the medical model. In some States, however, Medicaid-funded attendant programs are less medical in orientation than some Title XX-funded attendant programs.

The issue of consumer control raises the question of whether the consumer employs or directs the attendant. If the individual directs but does not actually pay or control the hiring and termination of the provider, there is doubt that they could truly control the service they receive. Providing funds directly to the individual who then pays the attendants of their choice, however, allows for misuse of the funds. It becomes a question of accountability for the expenditure of public funds versus control over hours, wages, and/or quality of services.

There is debate over what amount of publicly funded attendant services should be allowed per individual. In determining a minimum, there is a threshhold where finding and managing an attendant is more trouble than doing the activity

oneself (if that is possible) or having a family member do it. On the other extreme, if a person is given unlimited time for attendant services, abusive situations may arise since there is no incentive to eliminate unnecessary dependence on others.

The questions arise of how much a family can be reasonably expected to do for a disabled member and whether families should be paid for the attendant services they provide. The Liberty Mutual Insurance Company, a major carrier for workers' compensation, found that the spouses of spinal cord injured persons experienced high rates of burnout when they also functioned as attendants. Some years ago, Liberty Mutual found that by paying the spouses $5,000 per year either to hire an attendant or to reimburse themselves, more marriages remained intact and institutionalization was averted. However, paying families for attendant services encourages dependency. This issue is highly influenced by cultural values regarding family responsibility. For example, attendant-type activities are considered the responsibility of the family to a greater extent among some strongly ethnic populations, such as Mexican-Americans, and in rural areas than among urban white persons. Paying an attendant allowance in the form of a voucher to the disabled individual if he or she is of an appropriate age and has the cognitive ability to manage an attendant could solve the problem.

The comment has been made that one could never pay attendants what they are worth, so critical is their service to the productivity and even survival of severely disabled people.

Yet in our society, they are not generally given high status and are usually paid minimum wage. To improve their status and to create a larger pool of quality persons willing to serve as attendants, there should be better marketing of the service and its providers. Attendant services legislation should be constructed so as to ensure that attendants receive adequate wages and benefits.

In order to make the pool of attendants more available to persons who need their services, a registry should be developed in each locality listing individuals with various qualifications who are interested in serving as attendants, similar to registries of interpreters for deaf persons. Attendant services legislation should be worded so as to allow funds for attendant training as one means of making available a pool of attendants with a variety of qualifications. There is general agreement, however, against requiring specific credentials of attendants.

D. Funding

Funding for attendant services come from a variety of sources. Eligibility requirements vary for each type of funding. Some authorities suggest that these services should be coordinated by pooling funds under a single authority and requiring their administration by a single agency. Others feel that a more productive route would be to tap existing Federal and State funds. Federal funds which currently support long-term care institutions could be redirected, as could certain Title XX funds for community services. Within existing programs, definitions and eligibility criteria could be expanded to include more persons who need attendant services. Demonstration line items in

Federal and State agency budgets could be used to support demonstration/utilization/dissemination projects as a means for establishing an expandable foundation for national and State-wide service systems.

A major source of funding for attendant services is the Social Security Act. While the exact amount expended for attendant services under this Act is almost impossible to ascertain, the amount is estimated to be substantial. Anyone who is eligible for Medicaid or Medicare benefits can apply for attendant services through the State administering agency and can receive funding for services if they meet the strict eligibility criteria. The specific titles of the Act under which attendant services could be obtained are as follows:

- Title II: Old Age and Surviving Dependents Insurance. Medicare eligibility could be extended to disabled beneficiaries who engage in substantial gainful activity despite continuing disabilities.

- Title V: Maternal and Child Health/Crippled Children Services. Maternal and Child Health discretionary funds could be used to demonstrate the value of attendant services for adolescents to achieve peer integration and independence. States should be encouraged to provide attendant services in order to reduce hospitalization. The term "disabled" should replace "crippled."

- Title XVI: Supplemental Security Income(SSI). SSI benefits for SSI disabled beneficiaries who require some attendant services could be increased to allow for the expense of attendant services, as is done under the Veterans Administration "essential persons" provision. Similar increases in State supplements could be encouraged. Section 1619 (a) (b), a demonstration project whereby disabled beneficiaries can return to or attempt work and still maintain their Medicaid eligibility, could be made a permanent part of the Act and extended to cover Medicare eligibility as well.

- Title XVIII: Medicare. Coverage of home health services beyond those who are labeled "home bound" could be liberalized and the requirement that a

skilled nurse either provide or supervise these services could be eliminated. Time-limited attendant services to persons leaving hospitals or use of extended care facilities could be extended.

- o Title XIX: Medicaid. Inclusion of attendant services could be made mandatory under State plans. The income limit could be increased for those labeled "medically needy" to 133% of SSI level, as opposed to the AFDC level (including State SSI supplements). Independent living centers could be included as providers of attendant services. The requirement that services be delivered in the individual's "own home," thus limiting their mobility in the community, could be eliminated.

- o Title XX: Social Services Block Grant. Attendant services could have authorization and appropriations for additional funding earmarked for three to five years.

There is doubt that attendant programs funded solely by Titles XVIII, XIX, or XX could eliminate their traditional means-tested eligibility and subsequent work disincentives. Funds from Title VII Part A of the Rehabilitation Act could be used to provide attendant services to disabled persons not eligible for services under the Social Security Act. Other sources of block grant funds and/or State funding could be explored for providing attendant services in a cost sharing arrangement in which, for example, individuals would pay no more than 5% of their income for the services they need. The issue is the separation of eligibility for health and social services from eligibility for income benefits to avert work disincentives.

As a mechanism for disbursing the funds, a type of block grant could be given with a State matching requirement. Funds should be redistributive to equalize services throughout the

States, but wealthier States could enrich their programs, as is currently being done with Supplemental Security Income. Block grants could be part of a long-term care policy for elderly and disabled persons. There is some concern, however, that block grants of Federal money for this purpose could discourage States from establishing programs with pure State money.

E. Cost of Meeting the Demand for Attendant Services

Using DeJong's estimate of the demand for attendant services among working age disabled persons (150 per million population) and statistics from the Current Population Survey (1984) (147 million persons between the ages of 16 and 64), it can be conservatively estimated that 22,050 persons would use attendant services if they were available.

The Metrolina Independent Living Center in Charlotte, North Carolina, conducted a demonstration independent living project using foundation funding. Among all the services delivered in a one year period (July 1, 1984 - June 30, 1985), a total of $64,600 was spent on attendant services for 16 clients at an average of $4040 per year per person; an average of 18.5 hours of service was used per week per person at $4.55 per hour. By applying these usage and payment rates to the national estimate of 22,050 persons needing attendant services, an estimated $96.5 million annually could meet the demand for this service among working age persons.

V. A NATIONAL POLICY FOR ATTENDANT SERVICES

The subject of attendant services was discussed by leaders in the independent living movement and among service providers at three conferences in 1984 and 1985 sponsored by the Independent Living Research Utilization, World Rehabilitation Fund, and National Council on the Handicapped. Each gathering of experts called for a comprehensive national policy for attendant services. With each conference building on the work of the previous one, the following policy guidelines were developed for Federal funding to support a national system of attendant services. The system should:

Serve People with All Types of Disabilities on the Basis of Functional Need. Attendant services have traditionally been designed to meet the needs of physically disabled persons. The concept, however, is applicable to any assistance which compensates for an individual's functional limitation. In this sense, interpreters for deaf persons, readers for blind persons, and supervisors for mentally impaired persons fit within this category.

The need for extensive assistance by persons with severe, multiple impairments is the obvious extreme of this dimension. Persons with less severe limitations may have need of attendant services for small amounts of time or only periodically. However, this relatively minor need may be a crucial link in their independence support system.

Serve People of All Ages. Parents should have the option of having a nonfamily member assist in the care of their disabled child on an occasional, part-time, or full-time basis. Disabled

adolescents should have the opportunity of learning to productively manage attendants as part of the transition from school to life in the community. Older persons who have lost certain functional abilities should have the option of utilizing the services of an attendant in order to maintain independence in their own home.

Provide for the Optimum Degree of Self-Direction and Self-Reliance as Appropriate for Individual Consumers. Maximum self-direction involves locating, interviewing, screening, hiring, managing, paying, evaluating, and terminating attendants. Functions such as locating, interviewing, and screening may be performed by an agency or other third party while the individual maintains control of others such as hiring, management, payment, and termination. For persons with limited cognitive function, more third party involvement and supervision may be required; however, control may still be maintained within the abilities of the individual.

Be Accessible to People at All Income and Asset Levels with Cost Sharing as Appropriate. Persons with income or resources near or in excess of the maximum amount for eligibility under certain federally-funded attendant service programs should have the option of purchasing any service offered through publicly funded attendant service providers on a sliding fee or other type of cost sharing basis. An individual should have access to referral and training services, for example, even if they fund the services of the attendant themselves.

Include Assistance with Personal, Cognitive, Communicative, Domestic, and Other Related Services. Activities may include personal or self care (including communication), home care and cognitive tasks, as mentioned in the above definition of attendant services, or assistance with any other tasks which are critical to the maintenance of independence and productivity for persons with any type of disability.

Include 24 Hour, 7 Day/Week Services, Short Term (Respite), and Emergency Assistance as Needed. Attendant services should be regarded as life-sustaining services, and therefore should not have restricted hours for delivery. Service systems should have attendants available on a short term and emergency basis to cover inevitable gaps in the personal support systems of severely disabled individuals.

Be Available Wherever Needed (e.g., Home, Work, School, Recreation, Travel). Services should be available at home, at the workplace, and away from the location of the primary residence. Funding requirements should not limit the geographic mobility of the individual. For example, an individual receiving State funds for their attendant should be able to travel outside of the State and continue to receive the services of that attendant while they travel.

Not Create Disincentives to Employment. Eligibility for receiving attendant service funds should be based on very liberal income and asset maximum requirements, using gross income estimates adjusted for all disability-related expenses. The private sector should explore the possibility of making attendant services available at the work site as an employment incentive

for severely disabled persons.

Offer the Consumer a Range of Employer/Employee and Contract Agency Relationships. Consumers should be able to use the Federal funds for which they are eligible to hire attendants on a drop-in or live-in basis or to use any type of employer/employee relationship that is appropriate to their need and preference. They should have the option of contracting services on a long-term regular or periodic basis, or for a short, finite length of time with individuals located, screened, trained and hired by themselves or through a contract agency.

Provide for Outreach and Training of Consumers as Needed. Effective utilization of attendant services requires consumer awareness of the existence and availability of services, and how attendants can help them live more independently and productively. Public information and education activities should be conducted by provider agencies. Many consumers need training in how to effectively use attendant services and how to maintain productive relationships with their attendants.

Provide for Training of Administrators and Staff of Provider Organizations, with an Emphasis on Preparing Organizations Directed and Staffed Primarily by Persons with Disabilities to Provide Attendant Services. Because of the newness of attendant services as a human service profession and service-providing system, and because the independent living philosophy should guide the services being delivered, it is unlikely that traditional program administrators and staff will have the knowledge or experience necessary to operate programs which will

uphold these policies. Training is therefore essential to prepare persons with disabilities and consumer-controlled organizations to provide attendant services and to educate attendants and those who use their services. This type of training should be provided for in funding legislation and regulations. Qualified disabled persons who use attendant services should play a significant role in this training nationwide.

Provide for Recruitment and Training of Attendants as Needed. Some disabled persons prefer to hire totally untrained attendants and personally train them to meet their specific needs. Others prefer to know that the persons they interview have been screened by a third party according to certain personal and experience criteria. Those with mental impairments who require assistance in financial management and adherence to medication schedules will need attendants who can pass very strict tests of character, reliability, and experience.

Provide Reasonable Wages and Basic Benefits for Attendants. Attendants should be paid at least minimum wage or a salary similar to that of a provider of comparable services. Opportunities should exist for advancement and increases in salary with increases in qualifications and experience. A mechanism should be developed to assist consumers and provider agencies to offer attendants appropriate benefit packages.

Require Significant Participation of Consumers in Program Policy Determination and Administration. This is a unique and complex area in which consumer control is a foundational element in the philosophy underlying this service. Therefore, it is vital that persons who use attendant services be integrally involved in all levels of policy determination and administration of attendant service programs.

VI. RECOMMENDATIONS

In reviewing the programs services funded by the Federal government, the Council has found that there is an undue reliance on institutional care. The Council believes that personal assistance, as rendered by attendants, readers, interpreters, and advocates, when provided in conjunction with other community-based services, can be an effective and economical means for reducing this Nation's reliance on institutions and enabling most persons with disabilities to live independently in settings of their choice. The goal should be to establish self-directed personal assistant services as one component of a comprehensive array of community-based services that should be available to people with disabilities.

People with severe disabilities have a long-term need for support services. Stable funding and a coordinated system for providing personal services are needed if our society is to develop effective community-based alternatives to institutional care. The Council believes that the following recommendations are essential first steps in reaching this goal.

1. Congress should establish a national policy that defines personal assistance and should require the development of national standards for the delivery of personal services.

A national personal assistance policy should be developed to assure that programs offering personal assistance are required to:

- Serve people with all types of disabilities on the basis of functional need,
- Serve people of all ages,
- Provide for the optimum degree of self-direction and

self-reliance as appropriate for individual consumers,

- Be accessible to people at all income and asset levels with cost sharing as appropriate,
- Include assistance with personal, cognitive, communicative, domestic, and other related services
- Include 24 hour, 7 day a week service, short-term (respite), and emergency assistance as needed,
- Be available where needed (e.g., home, work, school, recreation, travel),
- Not create disincentives to employment,
- Offer the consumer a range of employer/employee and contract agency relationships,
- Provide for outreach and training of consumers as needed,
- Provide for training of administrators and staff of provider organizations with an emphasis on preparing organizations directed and staffed primarily by persons with disabilities to provide personal services,
- Provide for reasonable wages and basic benefits for personal assistants, readers, and interpreters, and
- Require significant participation of consumers in program policy determination and administration.

The development of a coordinated, effective approach to the delivery of personal assistant services requires that a comprehensive definition of these services be incorporated into the Social Security Act, the Rehabilitation Act of 1973, the Education for All Handicapped Children Act (P.L. 94-142), the Developmental Disabilities Act, the Older Americans Act, and Veterans benefits legislation. This definition should be a product of discussions between representatives of major disability groups.

A national policy-making body should set standards for the expenditure of personal assistant service funds to assure that these services are self-directed and responsive to the varied

needs of disabled persons and their families.

2. Congress should require the Social Security Administration, in consultation with the National Council on the Handicapped, to implement a series of projects, using SSA demonstration authority and targeting currently available funds, to develop and demonstrate a cost-effective process and mechanisms for the support of community-based personal assistant services for persons with severe disabilities.

The rechanneling of some of the funds that support institutions to support the development of consumer-directed, community-based systems for the delivery of personal assistant services, as rendered by attendants, readers, and interpreters, is a challenging task. It will require careful preparation and step-by-step implementation. The Council believes that a series of demonstration projects would be a productive approach to developing a cost-effective national system of personal assistant services.

A major portion of the resources which support persons with severe disabilities in institutional settings comes from Title XIX of the Social Security Act. While other provisions of this Act enable people with disabilities to receive a variety of social services and income support benefits, strict eligibility requirements regarding income and the involvement of medical professionals in the delivery of services hinder the ability of disabled people to live independently. For a substantial portion of these individuals, lives of considerably more independence and productivity would be possible if funding currently consumed by institutions and services requiring medical supervision could be made available for personal assistant services.

Changes in the language in specific titles of the Social

Security Act could have far-reaching economic implications. Such changes should be preceded by comprehensive studies of the most cost-effective methods for increasing funding for personal assistant services and ensuring that the guidelines for a national personal assistance system are upheld. These studies should significantly involve the input of persons with disabilities in all phases including planning and evaluation.

The recommended projects should be funded under the demonstration authority of the Social Security Administration using currently available funds. While funded by SSA, such projects should address the needs of persons who do not qualify for Social Security benefits as well as those who do. Such projects should:

a. Determine the extent of the national need for personal assistance,

b. Determine the cost of providing services to meet that need,

c. Determine the efficacy of personal assistant services models,

d. Determine the cost-effectiveness of a national personal assistance service plan,

e. Determine the feasibility of implementing a national personal assistance service plan, and

f. Determine the ultimate implications for the Federal budget by evaluating potential savings through reduced institutional costs and enhanced income from increased taxes as personal assistance services enable severely disabled persons to become employed or to live outside of institutions.

These demonstration projects should be carefully designed and evaluated since they would help establish the parameters of a national attendant services program.

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